

**CANCER-SPECIFIC DISTRESS AND COPING AS PREDICTORS OF EARLY  
DETECTION BEHAVIORS IN WOMEN AT FAMILIAL RISK FOR BREAST CANCER**

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# **CANCER-SPECIFIC DISTRESS AND COPING AS PREDICTORS OF EARLY DETECTION BEHAVIORS IN WOMEN AT FAMILIAL RISK FOR BREAST CANCER**

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Curative treatment for breast cancer has been highly successful when cancerous cells are detected in their earliest stages. Utilization of breast cancer early detection behaviors is crucial for all women, but these behaviors are especially relevant for women at familial risk for the disease. This study aimed to identify factors associated with utilization of early detection behaviors in a community sample of women at familial risk for breast cancer ( $n = 116$ ). Death of the relative was significantly linked with increased reports of cancer-specific distress regarding breast cancer risk, but it was not associated with increased use of early detection behaviors. Taking care of an ill relative and being an adolescent when the relative was diagnosed were not associated with either reporting cancer-specific distress or using early detection behaviors. Cancer-specific distress was not found to be a significant predictor of early detection behaviors. Problem-focused coping was positively associated with use of early detection behaviors whereas emotion-focused coping was negatively linked with use of early detection behaviors. These results suggest that coping interventions may be appropriate in order to encourage the use of early detection behaviors among women at familial risk for breast cancer. Future directions and limitations to the present study are discussed.

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## **1.0 INTRODUCTION**

Breast cancer is the second most common cancer and the second leading cause of cancer death among women. Among American women, the lifetime incidence rate of breast cancer is approximately 12.5%, with a 3.3% chance of dying from the disease. In 2006 alone, it was expected that 212,920 women would be diagnosed with invasive breast cancer. Approximately 40,970 women were expected to die from the disease, with only lung cancer causing more cancer deaths. As of 2006, there are believed to be over 2 million women living in the United States who have received treatment for breast cancer (American Cancer Society, 2006b). Due to the adverse effects of such treatment, cancer is viewed as one of the most feared of all diseases (Spittle & Morgan, 1999). Fortunately, advances in science and technology have dramatically decreased cancer mortality when it is detected in its early stages. Improved knowledge of risk assessment, prevention measures, and early detection strategies are three arenas that have been particularly useful in achieving decreases in breast cancer mortality. Curative treatment for early stage breast cancer has become highly successful, making it crucial to focus on promotion of behaviors that allows cancer to be detected in its earliest stages.

For breast cancer, a number of effective and useful methods of early detection may be portrayed as expensive, unpleasant, or time intensive. Aggressive surveillance for pre-cancerous growth in the breast is most appropriate for women who have risk factors for the disease and is especially relevant for women with a family history of breast cancer. Healthy women who have a

first-degree relative with breast cancer are two to three times more likely to develop breast cancer in their lifetimes than women without an affected first degree relative (Anderson, 1992; Slattery & Kerber, 1993). Although there are apparent advantages to utilizing early detection behaviors such as breast self- examination, clinical breast examination, and mammography in this population, psychological variables have been found to interfere with appropriate use. Cancer-specific distress and maladaptive coping strategies are examples of psychological factors that affect the decision making processes among women at risk for breast cancer (e.g. Lerman et al., 1993; Cohen, 2002). In addition, it is possible that potentially stressful factors such as past caregiving experience, a woman's age when her relative was diagnosed, and death of her affected relative may cause distress that may interfere with optimal use of early detection behaviors. This study aims to investigate the effects of caregiving, death of the affected relative, and adolescent age when the relative was diagnosed on cancer-specific distress. Furthermore, this study intends to investigate the extent to which cancer-specific distress affects or mediates the relationship between caregiving, death of the affected relative and adolescent age when the relative was diagnosed with use of early detection behaviors (breast self- examination, clinical breast examination, and mammography). We will also examine the extent to which the more frequent use of problem-focused or emotion-focused coping affects or moderates the relationship between cancer-specific distress and the use of early detection behaviors.



## **1.1 CANCER-SPECIFIC DISTRESS**

Because cancer is a potentially fatal disease with an unpredictable disease course, and its treatments are often aversive and debilitating, cancer risk can engender distress among those at risk. Distress is a response to appraisal of a threatening situation and an individual's ability to manage it. In the cancer context, cancer-specific distress is a patient's or loved one's response to cancer as a stressor. Cancer-specific distress is defined in the literature as an index of how upsetting or psychologically debilitating the disease (or risk) may be, and it is often operationalized as the amount of intrusive and avoidant thoughts in response to cancer-related cues (e.g. van Dooren et al., 2005). Distress related to cancer may be viewed as a normative response to increased risk and salient experiences with the disease (Hay et al., 2004). However, typical cancer-specific distress may be augmented by factors such as maladaptive coping, incorrect perceptions of future risk and vulnerability, negative body image, and feelings of fear and uncertainty (e.g. Brain et al., 2006).

Cancer-specific distress has been recognized on a diagnostic level since 1994 when cancer diagnosis was listed as a potential traumatic event in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). Thus, under DSM-IV criteria, an experience with cancer can be characterized as involving actual or threatened death or serious injury, or a threat to the physical integrity of self or others. Additionally, the person's response to the experience with cancer is thought to involve intense fear, helplessness, or horror. Symptoms of the cancer-related stress disorder include: persistently re-experiencing the event, avoidance of stimuli associated with the event, and persistent symptoms of increased arousal lasting more than one month. The disorder may be labeled as acute if the symptoms last less than 3 months or chronic

if the symptoms last more than 3 months. A delayed onset form of the disorder occurs if the onset of symptoms is at least 6 months after the incident.

Whether among populations of cancer patients or among those at high-risk for cancer, different levels of cancer-specific distress have been linked with various behavioral implications. For some, cancer-specific distress may be motivation to learn more about one's diagnosis or risk, yet for others it may act as a deterrent regarding health information (Miller, 1995). Extreme cancer-specific distress can lead people to avoid, ignore, or otherwise stop worrying about their risk. On a physiological level, cancer-specific distress has been linked with decreased natural cytotoxic activity, decreased secretions of TH1 cytokines, and elevated levels of stress hormones (Cohen et al., 2002). Moreover, cancer-specific distress may influence the cognitive processing of cancer related information (Erblich et al., 2003).

## **1.2 INFLUENCE OF FAMILY HISTORY OF BREAST CANCER**

Cancer-specific distress among women at risk for breast cancer may come from many sources. For one, the prospect of developing a life-threatening disease may be especially threatening to women who witnessed a loved one's breast cancer experience. The diagnosis of breast cancer in a family member may also challenge family dynamics depending how involved the relative was in the situation. Additionally, women at familial risk may grossly overestimate their perceived risk of developing breast cancer, which may also engender distress (Zakowski et al., 1997). Regardless of the time since the relative's diagnosis, distress related to breast cancer seems to be enduring among women at a familial risk for breast cancer (e.g. Erblich et al., 2003; Baider et al., 1999).

Cancer-specific distress has been identified in several studies as a concern among at-risk women. Valdimarsdottir (1995) found that women at familial risk for breast cancer had higher levels of intrusive thoughts and avoidance about breast cancer at both a pre-mammography timepoint and a 1 month follow up after receiving negative results. In support of this theory, Kash et al. (1992) found that 27% of women with family histories of breast cancer reported levels of distress worthy of psychological counseling. In a study by Lerman et al. (1993), approximately one- third of the sample who had a first degree relative with breast cancer reported having such significant worry about getting breast cancer that it interfered with their daily life. In fact, some of the women from this study had intrusive thoughts comparable to women diagnosed with breast cancer (Lerman et al., 1993).

Daughters and sisters of women with cancer have been shown to have physiological and emotional reactions directly and indirectly related to their distress about cancer (e.g. Cohen et al., 2002). Emotionally, daughters and sisters share similar fears regarding their relative's breast cancer experience. These fears include fear of breast cancer, fear of death from breast cancer, fear of loss of functioning, and fear of damage to the body and body image. Raveis and Pretter (2005) targeted three main factors that contribute specifically to adult daughters' distress: (1) emotional responses to the mother's diagnosis, (2) perceived changes in the mother- daughter relationship, and (3) perceptions of personal risk of breast cancer. In contrast, sisters of women affected by breast cancer view their risk as particularly salient since they most likely belong to the same generation and can easily identify with their sister affected by breast cancer. Van Dooren et al. (2005) found that having at least one sister affected with breast cancer was positively associated with breast cancer-specific distress. However, having only a mother affected with breast cancer was not associated with significant breast cancer-specific distress.

Further research is needed to supplement these preliminary findings by Van Dooren and colleagues. Since all first degree relatives of breast cancer patients may not experience significant cancer-specific distress (e.g. Coyne et al., 2000), it is important to understand how the relationship between distress and coping style may account for individual differences in cancer-specific distress in women at familial risk for breast cancer.

### **1.3 ASSOCIATIONS WITH CAREGIVING, AGE WHEN RELATIVE DIAGNOSED, AND DEATH OF THE RELATIVE**

While we know that psychosocial and physiological processes play an important role in adaptation to breast disease (e.g., Cohen et al., 2002; Kim et al., 2005), an area in need of study is the social context of illness for women who experienced their relative's breast cancer. In particular, there is a shortage of research investigating cancer-specific distress among women who were involved in the caregiving of their relative with breast cancer. A large amount of the caregiving research focuses on spouses of women with breast cancer and how in many cases they have reported equal or more distress compared to their partner. In many family structures, however, daughters and sisters are the family members who may be most likely to undertake caregiving responsibilities. Few studies assess the psychological and behavioral consequences of distress among these women who share a familial history of breast cancer and who were involved in the care of their relative with breast cancer.

Relatives of women diagnosed with breast cancer would be expected to have additional cancer-specific distress as compared to non-caregivers due to their at-risk status, as well as the additional psychological strain involved with caregiving. These feelings of distress have been

implicated in other diseases, such as Alzheimer's, in which the caregivers fear that the same fate awaits them in the future (Prohaska et al., 1987). Caregivers have also been found to experience distress due to "caregiver burden," which refers to negative aspects of giving care (Vitaliano et al., 1991). This burden interacts with the distress related to their loved one's change in functional ability, appearance, employment status, family and social role, and self- image, which are reported to have a direct impact on the caregiver (Siegel et al., 1991). Erbligh et al. (2000) provided preliminary evidence for this idea when he found that women with family histories of breast cancer who had cared for their mothers reported higher levels of cancer-specific distress than those who have not. However, these findings have not yet been replicated.

Limited evidence in the cancer arena suggests that adolescent girls at familial risk for breast cancer may be especially vulnerable to cancer-specific distress relative to other age groups. As compared to younger children, adolescents may be more cognitively aware of the debilitating effects of cancer and its treatment, as well as the role changes in the family setting as a result of the disease. Adolescents, in particular, may also possess a higher perceived vulnerability to cancer relative to other age groups (Compas et al., 1994). As compared to young adults, adolescents may be less able to cope with a relative's diagnosis and its implications. Adolescents are also likely to be more uncomfortable about involvement in their relative's breast cancer experience as compared to older age groups (Wellisch et al., 1992). Compas et al. (1994) reported that adolescent girls whose mother had cancer were the most significantly distressed group of children compared to gender mixed groups of young adult children, adolescents, and pre-adolescents whose parents had cancer. Compared to female adolescents in the general population, adolescent daughters of women with breast cancer reported significantly greater worries about their future health and risk for breast cancer. Furthermore, a study by Cappelli et

al. (2005) found that 85% of the adolescent daughters of women with breast cancer felt vulnerable to breast cancer, as compared to 10% of the general population group. While the research supports the fact that adolescent girls experience significantly higher cancer-specific distress compared to other age groups, it is unclear if the elevated cancer-specific distress is present in daughters and sisters during adulthood. Additionally, confirming these findings in the cancer context may be particularly interesting since research in other areas suggests that adolescents may feel invulnerable to health threats (e.g. Johnson et al., 2002).

Relatives of cancer patients are likely to have stressful experiences associated with their loved one's diagnosis. The emotional and physical debilitation associated with such experiences may be especially salient to individuals who lost a relative to cancer. Zakowski et al. (1997) found that among women with family histories of breast cancer, those with a parent who died of cancer experienced higher levels of intrusive thoughts, avoidance, and perceived risk as compared to those without a relative who died of breast cancer. Similar results were found by Erlich and colleagues (2000) who indicated that among women with a family history of breast cancer, those who lost their mother to breast cancer showed significantly higher distress levels than women whose mothers had not died of breast cancer and women without a family history of breast cancer. In other cancer populations, and women in the general population, positive associations have been found between number of family members who have died of cancer and increased personal risk estimates (Wardle, 1995). These feelings of increased perceived risk may contribute to increased feelings of distress among such women (e.g. Zakowski et al., 1997). While the limited amount of research focuses on daughters of women with breast cancer, sisters of women with breast cancer are likely to be susceptible to the same distress. Little research has been done, however, investigating cancer-specific distress among both daughters and sisters

whose relative died of breast cancer as compared to those with a relative who did not die of breast cancer.

## **1.4 COPING**

Coping style is an influential link between distress and behavior. By definition, coping is the implementation of a response to a physically or emotionally stressful situation (Lazarus & Folkman, 1984). The sequence of events surrounding the stressful situation yields positive and negative behavioral changes in the individual. Some people are motivated to change the stressor, while others tend to accommodate or reduce the effects of the stressor by safeguarding themselves from it. While there are many ways to classify coping, there is a general distinction between two broad categories, problem-focused coping and emotion-focused coping. Problem-focused coping is aimed at problem solving or making proactive attempts to alter the source of the stress. Examples of problem-focused coping include active coping, planning, positive reframing, acceptance, and seeking instrumental social support. Emotion-focused coping, on the other hand, focuses on reducing or dealing with the emotional stress that is elicited by or associated with the situation. Self-distraction, denial, substance use, use of emotional social support, religion, humor, behavioral disengagement, and a focus on venting of emotions may be characterized as emotion-focused coping strategies. Although most people engage in aspects of problem-focused and emotion-focused coping, these broad labels are convenient methods of grouping the most common coping strategies individuals use. Additionally, problem-focused and emotion-focused labels have been widely used in the literature as predictors of behavioral consequences.

Despite some exceptions, the majority of coping studies have shown that active, problem-focused coping is associated with better psychological adjustment among both patients and healthy individuals (e.g. Dougall et al., 2001). Alternately, emotion-focused coping has been associated with higher levels of negative affect across both groups (e.g. Lazarus, 2000). It is not clear whether this reflects the superiority of one approach or the differences in the types of stressful situations that elicit these types of coping. It is also important to note that specific coping strategies may be most beneficial in specific situations. Research by Baum et al. (1983) suggests that problem-focused coping is most adaptive when something can be done about the stressor, whereas emotion-focused coping may be more appropriate when the stressor is beyond one's control.

#### **1.4.1 Coping and breast cancer risk**

In the literature describing women at familial risk for breast cancer, the majority of studies indicate the use of problem-focused, confrontive, and optimistic coping among women with a family history of breast cancer (e.g. Wellisch et al., 1991; Lancaster, 2005). In fact, in comparison to women without a family history of breast cancer, daughters of women with breast cancer are more actively involved in the medical setting and seek out more medical information (Gilbar & Borovik, 1998). Among the studies reporting use of emotion-focused coping in this population, women who perceive their risk of getting breast cancer as high are likely to engage in emotion-focused coping (Bowen et al., 2003). Moreover, emotion-focused coping was directly associated with high levels of cancer-specific distress as compared to those who cope in other ways (Kim et al., 2003). Support for this association between cancer-related distress and emotion-focused coping has also been found among women with breast cancer. In particular,



Culver et al. (2004) found that distress among those diagnosed with breast cancer was associated with components of emotion-focused coping such as denial, behavioral disengagement, and self-distraction.

## **1.5 BREAST CANCER EARLY DETECTION AND DISTRESS**

Among women at increased risk for breast cancer, early detection behaviors such as mammography, clinical breast examinations, and breast self examinations (BSE) are important for early identification of cancer, which reduces the risk of dying from the disease. Overall, there is an association between receiving yearly mammograms and having a first degree relative with breast cancer (Hitchcock et al., 1995). However, regardless of risk level, Lerman et al. (1994) found that not all women comply with the recommended frequency of breast cancer early detection behaviors. For this reason, it is important to identify the psychological factors that may influence the use of early detection behaviors. Cancer-specific distress has been identified as a variable that may influence suboptimal screening behaviors (Lerman et al., 1993). There are mixed findings, however, concerning the influential effect of distress on breast cancer risk behaviors. Some argue that women who are aware that they have an increased risk for breast cancer may experience anxiety regarding their risk and be less likely to obtain breast cancer screenings (Kash et al., 1992). However, van Dooren et al. (2003) found that significant cancer-specific distress existed among women who performed BSE more frequently than normal (i.e. at least once a week) as compared to those who performed BSE at the recommended frequency. Unfortunately, it is unclear if the distress is a motivator, byproduct, or combination of the two, of

excessive screening. Thus, there is a link between cancer-specific distress and breast cancer screening frequency; however, it is unclear in which direction distress influences screening.

## **1.6 BREAST CANCER EARLY DETECTION AND COPING**

A majority of the literature on coping with breast cancer focuses on how women cope with a cancer diagnosis. In general, problem-focused coping has been associated with better adjustment in women with early and late stage breast cancer (e.g. Carver et al., 1993; Kershaw et al., 2004). Among the studies that have focused on the behavioral consequences of specific coping strategies among women at familial risk for breast cancer, problem-focused coping has also been related with favorable outcomes. On the whole, active, problem-focused coping regarding breast cancer risk has been found to have a significant influence on the optimal use of breast cancer early detection behaviors. Since measurements of problem-focused coping includes thoughts and behaviors that are active and plan for the future, it is likely that screenings are a way for the women to implement this type of coping. For instance, Cohen (2002) found that problem-focused coping predicted regular frequency of BSE whereas other forms of coping did not. In support of this idea, Bowen et al. (2003) found that problem-focused coping was associated with intention to undergo mammography, while alternate coping strategies were negatively associated with mammogram intentions. Coping is also relevant to this process as shown through use of a problem-focused coping intervention which led to a significant increase in BSE among first degree relatives of breast cancer patients (Audrain et al., 1999).

## **1.7 PURPOSE OF THE PROPOSED STUDY**

Many women at familial risk for breast cancer have been found to experience significant cancer-specific distress due to discomfort regarding their relative's cancer experience and worry that the same fate awaits them. Factors such as caregiving, adolescent age when the relative was diagnosed, and death of the relative may augment the distress related to a woman's cancer risk. Increased distress among these three subgroups of women at familial risk for breast cancer may influence the use of breast cancer early detection behaviors. Cancer-specific distress engendered by a woman's risk for breast cancer elicits coping strategies in order to deal with the stressor. Although certain coping strategies are related to use of early detection behaviors, it is not clear to what extent coping influences the relationship between cancer-specific distress and early detection behaviors. By investigating the relationship between cancer-specific distress, coping style, and early detection behaviors, we aim to identify factors that lead at-risk women to perform early detection behaviors. By targeting these influential psychosocial factors, we will pave the way for intervention studies tailored to specific subgroups of women at familial risk for breast cancer. In our analysis, we theorize that investigating the pathways of cancer-specific distress and coping strategies will predict the utilization of early detection behaviors among women at familial risk for breast cancer. Special attention will be given to caregiving, adolescent age when the relative was diagnosed, and death of the relative, and how these factors influence cancer-specific distress.

### **1.7.1 Aim 1 and hypothesis**

Aim 1 seeks to examine the effects of caregiving, death of a relative with breast cancer, and adolescent age of the subject when her relative was diagnosed on cancer-specific distress. We hypothesize that certain factors may be associated with greater cancer-related distress among women at familial risk for breast cancer. Women who were caregivers of their relative with breast cancer, lost their relative to breast cancer, or were adolescents when their relative was diagnosed will report significantly higher levels of cancer-specific distress than will high-risk women not in such categories. The three predictor variables (caregiving, death of the relative, and age of the subject when her relative was diagnosed) will each have an independent effect on cancer-specific distress.

### **1.7.2 Aim 2 and hypothesis**

Aim 2 will explore the extent to which cancer-specific distress mediates the association between caregiving, death of the relative, and adolescent age when the relative was diagnosed and the use of early detection behaviors will be examined. Due to the fact that we are not using a longitudinal design, we also plan to investigate the possibility that use of early detection strategies may mediate the association between our three predictors (caregiving, death of the relative, and adolescent age when the relative was diagnosed) and cancer-specific distress. We hypothesize that women who were caregivers of their relative with breast cancer, lost their relative to breast cancer, or were adolescents when their relative was diagnosed, will experience elevated distress regarding their cancer risk. Caregiving, death of the relative, and an adolescent age when the relative was diagnosed are also factors that will negatively influence the

appropriate use of early detection behaviors (breast self-examination, clinical breast examinations, and mammography). Cancer-specific distress will mediate the relationship between caregiving, death of the relative, and an adolescent age when the relative was diagnosed and recommended utilization of early detection behaviors. In the absence of a longitudinal design, it is also possible that early detection behaviors will mediate the relationship between these three predictors and cancer-specific distress.

### **1.7.3 Aim 3a and hypothesis**

Aim 3a seeks to examine the respective associations between problem-focused coping style and emotion-focused coping style with utilization of early detection behaviors. We hypothesize that the way that women cope with cancer-specific distress will be correlated with proper utilization of early detection behaviors. Specifically, increased use of problem-focused coping with cancer-specific distress will be associated with higher adherence to the recommended use of early detection behaviors. In contrast, increased use of emotion-focused coping with cancer-specific distress will be associated with lower adherence to the recommended use of early detection behaviors.

### **1.7.4 Aim 3b and hypothesis**

Aim 3b will examine the extent to which coping style moderates the relationship between cancer-specific distress and proper use of early detection strategies. We hypothesize that cancer-specific distress will be negatively associated with use of early detection behaviors among women at familial risk for breast cancer. The association between cancer-specific distress and

early detection behavior will be moderated by coping style. Specifically, women who utilize more problem-focused coping will show a lower negative association between cancer-specific distress and early detection behaviors than those who use less problem-focused coping. In contrast, women who utilize more emotion-focused coping will show an increased negative association between cancer-specific distress and early detection behavior compared to women who use less emotion-focused coping.

## **2.0 METHOD**

### **2.1 SAMPLE**

The sample consisted of 116 women recruited through the Risk- Reducing Behaviors among Women with a Family History of Breast Cancer study. This sample is a subset of a community sample of 187 subjects recruited using print and online media throughout Pittsburgh and the greater Pittsburgh area. Recruitment material described a \$35 payment for participating in the study and the opportunity to contribute to the research in the field of breast cancer prevention. Interested participants were instructed to contact the study coordinator by phone and were screened using a phone script. Participants had to meet the following criteria: a) female gender, b) ages 22 to 69, c) have had a biological mother or sister with breast cancer, d) no personal history of cancer, e) able to read and write English, and f) able to give informed consent. Participants were excluded if there was evidence of significant psychological dysfunction, prior neurological disease or injury, or education less than an eighth grade level.

### **2.2 INSTRUMENTS**

Demographic information was collected using a standard questionnaire used to obtain information on age, ethnicity, education, marital status, time since relative's diagnosis,

employment, income, and whether the relative was the subject's mother or sister. These variables were used to provide descriptive statistics and were controlled for in the study.

### **2.2.1 Predictor Variables**

Cancer-specific distress was measured with the intrusive subscale of the Impact of Event Scale-Revised (IES-R; Weiss & Marmar, 1997). The IES-R is a 22-item self report scale that assesses the experience of intrusive and avoidant thinking as well as hyperarousal symptoms related to a specific stressful event. The items on the scale are intended to be answered in response to a specific stressor. In this study, the stressor was noted as "being at a higher risk for the occurrence of breast cancer." The intrusive subscale has 7 questions consisting of question numbers 1, 2, 3, 6, 9, 14, 16, and 20. Each item has five answer categories: not at all (score 0), a little bit (score 1), moderately (score 2), quite a bit (score 3) and extremely (score 4). The intrusive subscale of the IES-R has been widely used in past studies to assess cancer-specific distress among women at familial risk for breast cancer and has shown good internal consistency ( $\alpha = .83-.89$ ; e.g. Erblisch et al., 2003).

Caregiving status was measured by a question asking: "To what degree were you involved in the caretaking of your relative?" The question was based on a 0=not at all to 4=a lot Likert-type scale. Caregiving was investigated as a continuous variable in the analyses. Death of the relative from breast cancer was measured using the following Yes/No questions: "If your mother had breast cancer, did she die as a result of breast cancer? If your sister had breast cancer, did she die as a result of breast cancer?" Age of the subject when their relative was diagnosed with breast cancer was measured using the question: "How old were you when your relative was diagnosed with breast cancer?" Women were included in the adolescent group if



they were between the ages of 11 to 19 when their relative was diagnosed with breast cancer. Women aged 0 to 10 when their relative was diagnosed were regarded as children. Women aged 20 and above when their relative was diagnosed formed the adult group. This age distribution is consistent with ranges used by other researchers investigating adolescents in this type of sample (e.g. Cappelli et al., 2005; Lewis & Hammond, 1996).

Coping was measured using the Brief COPE Inventory, which assesses how people respond to stressful events in their lives (Carver et al., 1989). The measure contains 28 questions and the response format is a 4-point Likert scale (1= not at all, 2=a little bit, 3= a medium amount, 4=a lot). The measure was administered in the situational-present format in which subjects rate the frequency of their response to an event up to the present. The event was “being at a higher risk for the occurrence of breast cancer.” The measure contains 14 scales on which individuals are coded: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Coping strategies were examined as part of the composite variables of problem-focused and emotion-focused coping. Problem-focused coping included active coping, planning, positive reframing, acceptance, and use of instrumental social support. Emotion-focused coping consisted of self-distraction, denial, substance use, use of emotional social support, behavioral disengagement, venting, humor, religion, and self-blame. Due to the fact that women may engage in both styles of coping, problem-focused and emotion-focused coping will be examined as continuous variables. Reliability analyses were performed for both scales and Cronbach’s  $\alpha = .86$  for the problem-focused group  $\alpha = .75$  for the emotion-focused scale.

### **2.2.2 Outcome Variable**

Early detection behaviors were assessed using a questionnaire designed by the researchers. Mammography, breast self-examination (BSE), and clinical breast examination were calculated and a composite score labeled as early detection behaviors was created. Past research has shown that self-reports of early detection use (e.g. mammography) are reliable ( $\alpha = .94$ ; King et al., 1990). In assessing compliance with the recommended guideline of one mammogram per year for women over 40 (ACS, 2006a), we asked subjects if they received a mammogram in the past year. As recommended in past literature (e.g. Aiken et al., 1994), we asked if their last mammogram was due to a breast problem or for screening purposes. Women who indicated that they had a mammogram for reasons other than screening purposes were not classified as adherent in data analyses. Women who indicated that they were under the age of 40 were asked if they had consulted a health care professional about the possibility of beginning mammography at an early age due to their family history of breast cancer. Response to this question was used to measure adherence for mammography in these women under 40 who do not report any history of mammography.

In order to assess the utilization of breast self-exam in our sample, we asked subjects to indicate if they performed BSE over the past 6 months. Consistent with recent studies (Erblich et al, 2003; Tang et al., 1999), performance was not measured by the monthly recommendation, which allows for regular BSE performers who may occasionally miss a performance. Additionally, in order to assess compliance with the recommended guidelines for clinical breast exams, subjects were asked a question relevant to their age. The American Cancer Society recommends a clinical breast exam approximately every 3 years for women in their 20s and 30s and every year for women ages 40 and over (ACS, 2006a). Correspondingly, women ages 22-39

who indicated receiving a CBE in the past 3 years and women ages 40 and over who indicated a CBE in the past year were considered adherent.

Similar to the companion study to this project, a composite outcome variable was used to determine a subject's overall adherence to early detection recommendations (Somers, 2006). Subjects received a "1" for adherence and a "0" for non- adherence for each early detection measure. For example, a woman under age 40 who performed BSE in the past 6 months, spoke to her health care provider about beginning mammograms at an early age, and did not have a CBE in the past three years received a composite score of "2."

## **2.3 PROCEDURE**

Potential subjects recruited through print and online media were instructed to contact the study coordinator by telephone to receive more information about the study. During the call, eligibility of the potential subject was assessed using the exclusionary criteria. If the individual was eligible, an appointment was made for the subject to complete the study. Study appointments took place at the University of Pittsburgh Cancer Institute Department of Behavioral Medicine and Oncology in Oakland. At the appointment, the subject was notified about the purpose of the study and informed consent was obtained. Once informed consent was obtained, the participant completed the self- report and early detection questionnaires. Participants who completed the study visit received compensation of \$35.

### **3.0 RESULTS**

#### **3.1 PARTICIPANTS**

The current study included 116 participants taken from a larger study sample of women at familial risk for breast cancer. Demographic information describing the sample is provided in Table 1. All participants were women having a mother or sister with breast cancer who reported no personal history of cancer. Participants were able to read and write English, and they provided informed consent. The sample was primarily composed of women whose mothers had breast cancer (82.8%), and the average time since their relative was diagnosed was 13.9 years ( $SD = 11.1$ ). Participants ranged in age from 22 to 69 years with a mean of 41.8 years ( $SD = 11.8$ ), and most were of European American ethnicity (72.4%). The highest percentages of women had some graduate level education (37.1%) and were married (56.9%). Although most women worked full-time (61.1%), the highest percentage had a total family income less than \$20,000 (29.3%).

Table 1. Demographics of the sample

Characteristic	N	%
Age (years)	41.8 (11.8) <sup>1</sup>	
Years since Relative's Diagnosis	13.9 (11.1) <sup>1</sup>	
Relative with Breast Cancer <sup>2</sup>		
<i>Mother</i>	96	82.8
<i>Sister</i>	20	17.2
Total Family Income		
0 - \$20,000	34	29.3
\$20,001 - \$40,000	32	27.6
\$40,000 - \$70,000	24	20.7
Over \$70,000	26	22.4
Education		
<i>High school graduate or less</i>	12	10.3
<i>Some college/Advanced vocational training</i>	31	26.7
<i>College degree</i>	30	25.9
<i>Some graduate work/Graduate degree</i>	43	37.1
Employment		
<i>Not working for pay</i>	20	17.3
<i>Part- time</i>	25	21.6
<i>Full- time</i>	71	61.1
Ethnicity		
<i>European American</i>	84	72.4
<i>Non- European American</i>	28	27.6
Marital Status		
<i>Never married</i>	50	43.1
<i>Married</i>	66	56.9

The distributions and descriptive statistics of the study variables were examined for normality, skewness, kurtosis and multicollinearity (see Table 2). Normality was examined using Levene's test, and all of the variables were normally distributed except cancer-specific distress.

**Table 2. Descriptive statistics of the sample**

	<b>Mean (SD)</b>	<b>Skewness</b>	<b>Kurtosis</b>
Caregiving	1.90 (1.50) <sup>1</sup>	-0.04	-2.03
Death of Relative			
<i>No</i>	85 (73) <sup>2</sup>		
<i>Yes</i>	31 (27) <sup>2</sup>		
Subject Age when Relative Diagnosed	29 (13) <sup>1</sup>	0.29	0.02
<i>Adolescent (Age ≤ 19)</i>	89 (77) <sup>2</sup>		
<i>Adult (Age ≥ 20)</i>	27 (23) <sup>2</sup>		
Cancer- Specific Distress	0.47 (0.60) <sup>1</sup>	2.07	5.40
<i>No Distress (IES = 0)</i>	35(30) <sup>2</sup>		
<i>Distress (IES &gt; 0)</i>	81(70) <sup>2</sup>		
Problem- Focused Coping	2.50 (0.73) <sup>1</sup>	0.07	-0.53
Emotion- Focused Coping	1.67 (0.42) <sup>1</sup>	0.55	-0.26
Early Detection Behaviors	4.84 (1.30) <sup>1</sup>	-1.10	0.66

<sup>1</sup> Raw scores

<sup>2</sup> N (%)

Cancer-specific distress was dichotomized and subjects were coded as having “no distress” if distress = 0 or “any distress” if distress > 0. A missing data analysis was conducted at the item-level for the relevant variables in the study. Because a pattern was not observed in the missing data, it was assumed that the data were missing at random. These data were imputed by Expectation Maximization (EM), which is a maximum likelihood approach that accounts for random error.

Women who were less than 11 years old when their relative was diagnosed were few ( $n = 7$ ), and thus were grouped with the women who were adolescents when their relative was diagnosed. Exploratory analyses investigated the prospect that women who had a relative diagnosed with breast cancer in the past year may have had different rates of early detection behaviors than women whose relative was diagnosed over a year ago. The mean time since

diagnosis was 13.9 years ( $SD = 11.1$ ), and an independent samples t-test showed no significant differences in utilization of early detection behaviors among the women who had relatives diagnosed in the past year ( $n = 8$ ) compared to the rest of the sample.

Correlations were used to explore the relationships among demographics and study variables (see Table 3). If demographics were found to be significantly correlated with outcome measures, they were entered as covariates in further analyses. Women who reported taking more care of their affected relative were more likely to have an ill mother than sister, were less educated, and were more likely to be non- European American. Those whose relative with breast cancer died were more likely to be older and non- European American. Women who were adolescents when their relative was diagnosed were younger, more likely to have a mother with breast cancer and to never have married. Older women reported less cancer-specific distress. Increased emotion-focused coping was associated with having decreased total family income, decreased education and being non- European American. Use of early detection behaviors was higher among older women and those with a higher total family income. In contrast, early detection behaviors were less common among non- European American women and women who were never married. Among the predictor variables, caregiving was associated with death of the relative ( $r = 0.26, p = 0.01$ ). Being an adolescent when the relative was diagnosed was not significantly associated with either taking care of the relative or death of the relative. Emotion-focused coping and problem-focused coping were positively correlated ( $r = 0.65, p < 0.01$ ).

**Table 3. Correlations between demographics and study variables**

	<i>Study Variables</i>						
	Caregiving	Death of Relative <sup>1</sup>	Adolescent when Relative Diagnosed <sup>1</sup>	Cancer-Specific Distress <sup>1</sup>	Problem- Focused Coping	Emotion- Focused- Coping	Early Detection Behaviors
<i>Demographics</i>							
Age (years)	0.14	0.20*	-0.33**	-0.20*	0.14	0.10	0.34**
Years since Relative's Diagnosis	-0.01	-0.02	-0.01	-0.13	0.02	-0.04	0.03
Relative with Breast Cancer							
<i>Mother</i>	0.29**	0.13	0.22**	0.12	0.01	0.11	0.11
<i>Sister</i> <sup>2</sup>							
Total Family Income	-0.15	0.00	-0.10	-0.18†	-0.02	-0.29**	0.34**
Education	-0.22**	-0.12	-0.03	-0.05	0.02	-0.23*	0.17†
Employment	-0.08	-0.11	-0.10	0.09	-0.04	0.12	-0.15
Ethnicity							
<i>Non- European American</i>	0.22*	0.33**	0.07	0.15	0.12	0.42**	-0.21**
<i>European American</i> <sup>2</sup>							
Marital Status							
<i>Never married</i>	0.01	-0.01	0.26**	0.08	-0.09	0.09	-0.24*
<i>Married</i> <sup>2</sup>							

Two- Tailed: \*\* P < 0.01; \* P < 0.05; † P < 0.10

<sup>1</sup> Dichotomized (0=No; 1=Yes)

<sup>2</sup> Comparison group for the other variable within this characteristic

Note: Higher scores on the measures indicate a higher value of the study variable



### 3.2 AIM 1

It was hypothesized that caregivers, those whose relatives died, and those who were adolescents when their relatives were diagnosed would have increased cancer-specific distress. Zero order correlations did not show significant associations between cancer-specific distress and caregiving or being an adolescent when the relative was diagnosed (see Table 4). However, those whose relative died of breast cancer reported increased cancer-specific distress ( $r = 0.23, p = 0.01$ ). When controlling for age, cancer-specific distress was significantly associated with more caregiving ( $pr = 0.20, p = 0.03$ ) and death of the relative ( $pr = 0.28, p < 0.01$ ).

**Table 4. Associations of study variables with cancer- specific distress**

	<i>Correlations</i>		<i>Logistic Regression</i> <sup>1</sup>		
	<b>Zero Order Correlation</b>	<b>Partial Correlation<sup>1</sup></b>	<b>β</b>	<b>Significance</b>	<b>Odds Ratio</b>
Caregiving	0.17	0.20*	0.23	0.13	1.26
Death of Relative	0.23*	0.28**	1.47	0.02	4.37
Adolescent when Relative Diagnosed	0.14	0.08	0.21	0.73	1.23

Two- Tailed: \*  $P < 0.05$ , \*\*  $P < 0.01$

<sup>1</sup> Age as a covariate

In order to test the proposed hypothesis further, logistic regression was used with cancer-specific distress as the outcome variable. The results are presented in Table 4. Because age was significantly correlated with cancer-specific distress, it was included as a covariate. Caregiving, death of the relative, and adolescent age of diagnosis were added in the same stage of the model. Neither being a caregiver nor being an adolescent when the relative was diagnosed significantly increased the probability of reporting cancer-specific distress. However, if a participant's relative died from breast cancer, she was significantly more likely to report cancer-specific distress ( $\beta =$

1.47,  $p = 0.02$ ) even when controlling for other variables. More specifically, women whose relative died had 4.37 greater odds of reporting cancer-specific distress than those women whose relative did not die. When the model was tested without age as a covariate, the likelihood of a woman whose relative died reporting cancer-specific distress only approached significance ( $p = 0.06$ ). Nagelkerke  $R^2$  values were compared in the models with age as a covariate and age as a covariate plus the predictors in order to test the degree to which the predictor variables influenced the prediction of cancer-specific distress. The  $R^2$  for the model with age alone was 0.06, and the  $R^2$  for the model including age and the predictors was 0.19. Thus, including the predictors in the model along with age provided an 13% better fit of the model predicting cancer-specific distress ( $\Delta R^2 = 0.13$ ).

### 3.3 AIM 2

It was hypothesized that caregiving, death of the relative, and being an adolescent when the relative was diagnosed would decrease the appropriate use of early detection behaviors, and that cancer-specific distress would mediate this relationship. Zero order correlations did not reveal a significant relationship between any of the predictor variables and use of early detection behaviors (see Table 5). Partial correlations controlling for age, total family income, ethnicity, and marital status, were also not significant. Linear regression controlling for these demographics found that caregiving, death of the relative, and age of the relative's diagnosis also did not significantly predict the use of early detection behaviors individually. The demographics alone were found to predict 27% of the variance in the use of early detection behaviors ( $R^2 = 0.27$ ). When the predictors were included in the regression model, the model explained 28% of

the variance in the use of early detection behaviors, which is only a change of 1% from the model including demographics only ( $R^2 = 0.28$ ,  $\Delta R^2 = 0.01$ ).

**Table 5. Associations of study variables with early detection behaviors**

	<i>Correlations</i>		<i>Linear Regression</i> <sup>1</sup>		<i>Linear Regression</i> <sup>1,2</sup>	
	<b>Zero Order Correlation</b>	<b>Partial Correlation<sup>1</sup></b>	<b><math>\beta</math></b>	<b>Significance</b>	<b><math>\beta</math></b>	<b>Significance</b>
Caregiving	0.00	0.04	0.04	0.66	0.04	0.66
Death of Relative	-0.02	-0.03	-0.04	0.69	-0.04	0.72
Adolescent when Relative Diagnosed	-0.14	0.07	0.02	0.87	0.02	0.87
Cancer- Specific Distress	-0.14	-0.01	---	---	-0.01	0.92

Two- Tailed: \*  $P < 0.05$ , \*\*  $P < 0.01$

<sup>1</sup> Age, total family income, ethnicity (compared to European American), and marital status (compared to Currently married) as covariates

<sup>2</sup> Cancer- Specific Distress as a predictor

It was proposed that cancer-specific distress would mediate the relationship between the predictor variables and early detection behaviors. This prediction was not examined because a significant relationship was not found between the predictor variables and early detection behaviors. However, in order to be thorough, the association between cancer-specific distress and early detection behaviors was examined. A zero order correlation and a partial correlation controlling for demographics did not show a significant relationship between cancer-specific distress and early detection behaviors (see Table 5). Cancer-specific distress was also entered in the linear regression model with the demographics and predictor variables, but it did not significantly predict the use of early detection behaviors.

We also planned to investigate the possibility that the use of early detection behaviors mediated the association between the three predictor variables and cancer-specific distress. Despite the low correlation between early detection behaviors and cancer-specific distress, mediation analyses were completed in order to be thorough. Early detection behaviors were thus added to the logistic regression model established in Aim 1 including demographics and the predictor variables (see Table 6). As seen in Table 4, death of the relative was the only predictor

variable found to significantly influence the probability of reporting cancer-specific distress, which made it eligible to test for mediation. When including early detection behaviors in the model, the relationship between death of the relative and cancer-specific distress did not significantly change as compared to the prior results (Table 6 vs. Table 4;  $\beta = 1.48$  vs.  $\beta = 1.47$ ), and the reported use of early detection behaviors was not found to significantly influence the probability of reporting cancer-specific distress. Including early detection behaviors in the regression equation did not significantly influence the change in the fit of the model including demographics and the three predictor variables ( $R^2 = 0.19$ ,  $\Delta R^2 = 0.00$ ). Thus, early detection behaviors did not mediate any association between death of the relative and cancer-specific distress.

**Table 6. Associations of study variables (including early detection behaviors) with cancer- specific distress**

	<i>Logistic Regression</i> <sup>1</sup>		
	$\beta$	Significance	Odds Ratio
Caregiving	0.23	0.13	1.26
Death of Relative	1.48	0.02	4.38
Adolescent when Relative Diagnosed	0.17	0.78	1.18
Early Detection Behaviors	-0.13	0.50	0.87

Two- Tailed; \*  $P < 0.05$ , \*\*  $P < 0.01$

<sup>1</sup> Age as a covariate

### 3.4 AIM 3A

It was hypothesized that reporting more use of problem-focused coping would be associated with increased adherence to the recommended use of early detection behaviors, and reporting more use of emotion-focused coping would be associated with decreased adherence to the

recommended use of early detection behaviors. Zero order correlations showed a significant, positive association between problem-focused coping and appropriate use of early detection behaviors ( $r = 0.19, p = 0.04$ ), and a negative, non-significant relationship was found between emotion-focused coping and appropriate use of early detection behaviors (see Table 7). When controlling for age, total family income, ethnicity, and marital status, a partial correlation also showed a significant relationship between problem-focused coping and use of early detection behaviors ( $r = 0.18, p = 0.05$ ). The association between emotion-focused coping and early detection behaviors was still not significant when controlling for demographics.

Linear regression was used to test the effects of coping style on the recommended use of early detection behaviors. The results listed in the top of Table 7 show a significant, positive relationship between problem-focused coping and early detection behaviors ( $\beta = 0.35, p = 0.00$ ) and a significant, negative relationship between emotion-focused coping and the use of early detection behaviors ( $\beta = -0.28, p = 0.03$ ). Given that the zero-order correlation between emotion-focused coping and early detection behaviors was not significant, these findings seem to reflect a suppression effect between problem-focused coping and emotion-focused coping. The magnitude of these relationships suggests moderate effects of coping on the use of early detection behaviors. The regression model including demographics, problem-focused coping, and emotion-focused coping was found to explain 28% of the variance in the use of early detection behaviors, which is an addition of 6% of variance from the model including demographics only ( $R^2 = 0.25, \Delta R^2 = 0.06$ ).

Problem-focused and emotion-focused coping were also analyzed as predictors in the full regression model established in Aim 2 (see bottom of Table 7). Use of more problem-focused coping remained significantly associated with more appropriate use of early detection behaviors

( $\beta = 0.38, p = 0.00$ ). Increased use of emotion-focused coping remained significantly related to less appropriate use of early detection behaviors, which again appeared to be due to a suppression effect ( $\beta = -0.30, p = 0.04$ ). Overall, the addition of coping styles into the full regression model added 7% more variability to the prediction of early detection behaviors as compared to the model that included demographics, the three predictor variables, and cancer-specific distress ( $R^2 = 0.29, \Delta R^2 = 0.07$ ).

**Table 7. Associations of study variables (including coping) with early detection behaviors**

<b>Initial Model</b>	<i>Correlations</i>		<i>Linear Regression</i> <sup>1</sup>	
	<b>Zero Order Correlation</b>	<b>Partial Correlation<sup>1</sup></b>	<b><math>\beta</math></b>	<b>Significance</b>
Problem- Focused Coping	0.19*	0.18*	0.35	0.00
Emotion- Focused Coping	-0.11	-0.01	-0.28	0.03
<i>Linear Regression</i> <sup>1</sup>				
<b>Full Model</b>			<b><math>\beta</math></b>	<b>Significance</b>
Caregiving			0.07	0.41
Death of Relative			-0.08	0.41
Adolescent when Relative Diagnosed			0.06	0.50
Cancer- Specific Distress			0.01	0.99
Problem- Focused Coping			0.38	0.00
Emotion- Focused Coping			-0.30	0.04

Two- Tailed: \*  $P < 0.05$ , \*\*  $P < 0.01$

<sup>1</sup> Age, total family income, ethnicity (compared to European American), and marital status (compared to Currently married) as covariates

### 3.5 AIM 3B

It was hypothesized that cancer-specific distress would be negatively associated with the use of early detection behaviors, and this relationship would be moderated by coping style. Linear regression was used to investigate the relationship between the cancer-specific distress X coping interaction terms and early detection behaviors. The initial model did not find a significant effect

of either the problem-focused coping and cancer-specific distress interaction or the emotion-focused coping and cancer-specific distress interaction on the use of early detection behaviors (see top of Table 8). The coping X cancer-specific distress interaction terms were also added to the full linear regression model established in Aim 3a in order to predict the use of early detection behaviors. The full regression also did not find that either the problem-focused coping X cancer-specific distress interaction or the emotion-focused coping X cancer-specific distress interaction had a significant effect on the use of early detection behaviors.

**Table 8. Associations of study variables (including coping X cancer- specific distress) with early detection behaviors**

<i>Linear Regression</i> <sup>1</sup>		
<b>Initial Model</b>		
	<b>β</b>	<b>Significance</b>
Cancer- Specific Distress	-0.05	0.62
Problem- Focused Coping	0.35	0.02
Emotion- Focused Coping	-0.34	0.04
Problem- Focused Coping X Cancer- Specific Distress	0.02	0.96
Emotion- Focused Coping X Cancer- Specific Distress	0.14	0.77
<i>Linear Regression</i> <sup>1</sup>		
<b>Full Model</b>		
	<b>β</b>	<b>Significance</b>
Caregiving	0.08	0.34
Death of Relative	-0.07	0.46
Adolescent when Relative Diagnosed	0.07	0.44
Cancer- Specific Distress	-0.06	0.60
Problem- Focused Coping	0.38	0.01
Emotion- Focused Coping	-0.36	0.04
Problem- Focused Coping X Cancer- Specific Distress	0.06	0.90
Emotion- Focused Coping X Cancer- Specific Distress	0.11	0.82

Two- Tailed: \* P < 0.05, \*\* P < 0.01

<sup>1</sup> Age, total family income, ethnicity (compared to European American), and marital status (compared to Currently married) as covariates

## **4.0 DISCUSSION**

The purpose of this study was to examine the associations between cancer-specific distress, coping, and early detection behavior utilization among women at familial risk for breast cancer. Although other studies have examined the relationship between distress, coping, and use of early detection behaviors, this study was unique due to the focus on caregivers, women who were adolescents when their relative was diagnosed and women whose relative died. The study had several main findings:

1. Taking care of a relative with breast cancer and being an adolescent when the relative was diagnosed did not increase the probability of reporting cancer-specific distress, but having a relative die of breast cancer was linked with an increased likelihood of reporting cancer-specific distress.
2. Taking care of a relative with breast cancer, being an adolescent when the relative was diagnosed, or having the relative die did not have a main effect on the appropriate use of early detection behaviors.
3. Cancer-specific distress did not significantly influence the appropriate use of early detection behaviors, and use of early detection behaviors also did not explain the relationship between death of the relative and cancer-specific distress.
4. Greater use of problem-focused coping was significantly associated with increased use of early detection behaviors. Increased emotion-focused coping had a negative



influence on use of early detection behaviors, and this relationship seems to be due to a suppression effect.

5. The hypothesized interactions between problem-focused coping and cancer-specific distress as well as emotion-focused coping and cancer-specific distress were not significantly associated with use of early detection behaviors.

#### **4.1 PREDICTOR VARIABLES AND CANCER-SPECIFIC DISTRESS**

Caregiving, age when the relative was diagnosed, and death of the relative were hypothesized to be linked with reports of increased cancer-specific distress among women at risk for breast cancer. Unexpectedly, being a caregiver of a woman with breast cancer did not increase a woman's probability of reporting distress about her own risk of breast cancer. In addition, regardless of whether a woman was an adolescent or adult when her relative was diagnosed, her reported level of cancer-specific distress did not differ. Consistent with the hypothesis, having a relative die from breast cancer increased the probability that a woman would experience distress related to her own risk of breast cancer.

Reports of increased cancer-specific distress from women whose relative died of cancer are not uncommon. Zakowski et al. (1997) found that among women at risk for breast cancer, those whose parents had died of cancer had the highest levels of intrusive thoughts, avoidance, and perceived risk regarding breast cancer. It is possible that the women who died of breast cancer had severe cases and may have experienced suffering related to their illness. Observation of this suffering and ultimate death, or simply knowing that it happened to their relative, may have instilled cancer-related fears among the relatives of women who died of breast cancer.

These findings imply that women whose relative died of breast cancer may benefit from tailored interventions to assist them in coping with their cancer-specific distress.

Our findings regarding distress levels among caregivers and women who were adolescents when their relative was diagnosed were consistent with past findings that some women who have a first-degree relative with breast cancer do not experience significant cancer-specific distress (Coyne et al., 2000). However, it is important to consider that the current sample had a very narrow distribution of cancer-specific distress, which led to a dichotomized distress variable. One may question the use of the IES-R as an appropriate questionnaire in order to detect the effects of cancer-specific distress. Although the IES-R has been used in past literature as a measure of cancer-specific distress, there is some concern to the degree to which it can detect minimal levels of cancer distress. The IES-R was developed in order to identify intrusive, avoidant, and hyperarousal symptoms related to the diagnosis of Posttraumatic Stress Disorder (PTSD). It is possible that the women in this sample did not experience clinically significant symptoms related to their relative's diagnosis, and thus, the IES-R may not have been sensitive to non-clinical levels of distress. Further testing of this hypothesis may benefit from a measure more sensitive to low levels of cancer-specific distress and also a larger sample size.

#### **4.2 PREDICTOR VARIABLES, EARLY DETECTION, AND CANCER-SPECIFIC DISTRESS**

When evaluating the use of early detection behaviors, there was not a main effect of taking care of the relative, adolescent age when the relative was diagnosed, or having the relative die. In fact, when these predictors were added to a regression model with the demographics, the addition of

the predictors barely increased the amount of variance explained. Partial correlations controlling for demographics did not show a significant relationship between these predictors and use of early detection behaviors. Taken together, these results suggest that other than demographic influences there may not be a significant relationship between the predictors and early detection behaviors among women at familial risk for breast cancer.

The frequency of use of early detection behaviors in the sample indicate that the average woman reported engaging in approximately 5 out of 6 of the early detection behaviors questioned. These findings support the work of Hitchcock et al. (1995) that show a positive association between having a relative with breast cancer and complying with the recommended frequency of early detection behaviors. However, compared to the American Cancer Society average of 51% of American women receiving breast cancer screenings in the past year (ACS, 2007), there may be some reason to believe that the women involved in the study were more compliant than the average American woman. It is possible that these elevated levels of compliance may have interfered with the identification of predictors of early detection behaviors. For instance, the predictive effects of caregiving, adolescent age when the relative was diagnosed, and death of the relative may have been masked by the fact that such compliant women were sampled. Further research is needed to target which specific groups may have difficulty with compliance. Also, caution should be used when interpreting these results since the use of a composite variable may not provide accurate information regarding which screening behaviors were used. Future work may benefit from looking at associations between predictor variables and each screening behavior separately.

Due to the lack of a significant relationship between the three predictors and early detection behaviors, it was not possible to examine cancer-specific distress as a mediator of this

relationship. Consequently, cancer-specific distress was examined as a predictor of early detection behaviors, and no main effect was detected. Since the presence of distress in the sample was minimal, it is difficult to determine if differing levels of cancer-specific distress would have better detected an effect on early detection behaviors. Looking at cancer-specific distress as a continuous variable with a larger range of distress values may be more conducive to detecting a significant relationship between distress and early detection behaviors.

Since the present study was cross-sectional, it was difficult to understand the temporal relationship between cancer-specific distress and early detection behaviors. For this reason, it was proposed that reported use of early detection behaviors be explored as a possible mediator of the relationship between death of the relative and cancer-specific distress. Since death of the relative did not have a direct effect on early detection behaviors, early detection behaviors were not able to be explored as a mediator. Nevertheless, the addition of early detection behaviors to a regression model including demographics and the predictor variables did not explain any additional variance in the prediction of cancer-specific distress as compared to the regression model including demographics and the predictor variables only. These findings may suggest that use of early detection behaviors does not affect the amount of distress that women have about their cancer risk. For instance, breast cancer screening may be perceived by some women as a routine medical procedure that is not linked with psychological implications. A more likely explanation for this null finding, however, is due to the small distribution of distress that was able to be tested.

### 4.3 COPING AND USE OF EARLY DETECTION

As hypothesized, problem-focused coping was found to be significantly linked with increased use of early detection behaviors, which is consistent with previous studies (e.g. Cohen, 2000; Bowen et al., 2003). Interestingly, use of emotion-focused coping had a significant negative influence on the use of early detection behaviors, but the effect appeared to be due to suppression. Suppression occurs when two independent predictors are so highly correlated that inclusion of one of the related variables in a regression equation increases the predictive validity of the other variable (Conger, 1974). In our study, problem-focused coping and emotion-focused coping were highly correlated ( $r = 0.65$ ). Zero order correlations confirmed that emotion-focused coping was a non-significant, negative predictor of early detection behaviors, and problem-focused coping was a significant positive predictor of early detection behaviors. Entering emotion-focused coping with problem-focused coping in the same regression equation resulted in a significant, negative relationship between emotion-focused coping and early detection behaviors and strengthened the significant, positive relationship between problem-focused coping and early detection behaviors. Thus, the inclusion of emotion-focused coping in the regression equation suppressed the related variance between problem-focused coping and emotion-focused coping. The suppression effect was reciprocal because it augmented the significant, positive relationship between problem-focused coping and early detection behaviors, and it strengthened the negative relationship between emotion-focused coping and early detection behaviors to significance. These findings suggest that if individuals cope with their risk in only a problem-focused way, they will be more likely to engage in early detection behaviors. Among individuals who cope with their risk of breast cancer by only expressing their emotions, there is no effect on use of early detection behaviors. However, due to the high correlation

between types of coping, it is assumed that people use aspects of both coping styles, and these types of coping should be analyzed together. When problem-focused coping and emotion-focused coping is used, problem-focused coping is linked with increased use of early detection behaviors and emotion-focused coping is linked with decreased use of early detection behaviors. These findings highlight the need to distinguish between problem-focused coping and emotion-focused coping as separate but coexisting predictors of early detection behaviors. In addition, in order to increase the proper use of early detection behaviors, interventions encouraging more problem-focused coping than emotion-focused coping may be beneficial.

Although past studies have established a link between coping and use of early detection behaviors, the present findings are interesting in light of the reports of low cancer-specific distress in this sample. According to the Brief COPE scores, on average, more women used problem-focused coping than emotion-focused coping (2.50 vs. 1.67). Since problem-focused coping was found to be associated with positive health behaviors, it may have been that the more frequent use of problem-focused coping influenced the levels of cancer-specific distress among these women. However, using our study design, it is difficult to understand the relationship between coping and distress. A longitudinal design would be useful in delineating the temporal order of the cancer-specific distress and coping relationship. This design would also be useful in testing interactions between coping styles and distress, which were not significant in our analyses. Current work in our laboratory, which includes follow-up assessments of these women, may provide useful information towards this end.

#### 4.4 LIMITATIONS

There are several limitations present in this study. The narrow range of cancer-specific distress represented in this sample is a major limitation. It is possible that when considering involvement in this study, women with the most distress regarding their cancer risk chose to decline participation. It is also possible that the women in this sample were able to cope effectively with their distress, and they did not experience significant distress regarding their cancer risk. One strategy to remedy this issue would be to have a larger sample size of women at risk for breast cancer in order to capture more variability in the reporting of cancer-specific distress. An increased sample size would also improve the power to detect effects, which was in the low range for the analyses in this study (0.20 - 0.30).

Another significant limitation to consider is the limited variability in the use of early detection behaviors. The women in this sample were extremely compliant, and it is not likely that all women at familial risk for breast cancer are as adherent to the recommended use of early detection behaviors. Although efforts were made to recruit diverse women throughout the community, it was likely that there was a bias in the use of breast cancer screening among those women who chose to participate. In order to get an accurate idea of factors that influence use of early detection behaviors and allow translation to the general population, it will be necessary to obtain a sample with a wider range of use of early detection behaviors. Additionally, although there was a wide-range of income reported in this study, women were generally well-educated and employed with full- time work. Future work investigating use of early detection behaviors should seek to procure a more diverse sample so that findings are able to generalize to a larger population.

A final limitation is that the study is cross-sectional, which does not allow for causal relationships to be established among the variables. Follow-up data has been recently collected from the participants in order to understand the impact of distress and coping on early detection behaviors over time. By using a longitudinal design, one would be able to better understand the temporal sequence of the predictors' effects on early detection behaviors. Given these limitations, future studies are needed in order to understand the relationship between factors associated with familial risk of breast cancer, cancer-specific distress, coping, and early detection behaviors.



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